# *Research Integrity and the Direct Involvement of Persons with Disabilities*

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Teaching students in the health, human service and education professions to be responsible in their interactions with persons with disabilities, as service providers and researchers, poses unique challenges to educators to move beyond imparting knowledge to impacting attitudes, values and ethics. Recent emphasis on outcomes of professional education programs most frequently focuses on indices of cognitive achievement and performance of specific skills or competencies. Measures of affective learning, or student attitudes and values toward the persons they serve, are less frequent and more difficult to document. Universities need to educate professionals who are capable of the responsible conduct of research. Pre-service education models are shifting from a traditional didactic approach to the use of case studies and problem solving, in an effort to influence affective learning and the application of knowledge and skills in real-life simulations. Studies of effective teaching methods to prepare professionals in the area of responsible conduct of research with human subjects are clearly needed. Person-focused learning approaches developed from interactive teaching models, used increasingly in pre-service education in disability services and programs. The use of case studies tends to promote application of theoretical knowledge and positive changes in affective learning, or students' attitudes and values.

Person-focused learning approaches move beyond case studies and directly include persons with disabilities and family members as partners. Research and teaching-involving people with disabilities assume that validity is strengthened through the direct involvement of people who experience disability daily (1). Kvale and Burns discuss threats to validity and the need to reconceptualize validity in qualitative research (2, 3). Due to the integral involvement of the researcher to conduct qualitative research, Kvale argued that qualitative research requires attentiveness to the concept of validity and its social construction with constant reference to the values, attitudes and experiences of the researcher and participants (2). Further, qualitative research methodology applies to interactive teaching, in which themes are explored and developed based on real-life scenarios (4). Participatory action research, a qualitative research process, directly involves key stakeholders in all phases of investigation (5, 1). In the present study, partnerships with persons with disabilities and family members began and continued throughout the design, implementation, and evaluation of co-teaching activities.

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The goal of the present study is to demonstrate and evaluate an interactive teaching method that directly involves people with disabilities and their family members and the impact of this model on students' attitudes and values, or on affective learning. Although the use of case study approaches in college level teaching, particularly with persons with disabilities, produces positive student learning outcomes, the differences in approaches to the uses of case studies are not explored. Specifically, the researchers sought to examine the effectiveness of person-focused learning to promote the responsible conduct of research among graduate, post-graduate and doctoral students.

Three major developments in policy, program development and teaching practices led to the development of person-focused learning. First, shifts in legislation and policy began in the 1950's and 1960's in the US, which continues today with increasing emphasis and advocacy for the rights of people with disabilities to have equal access to all arenas of community life. Second, increasing focus on rights and advocacy for people with disabilities contributed to the self-determination movement that places decision-making and life choices with the people affected, people with disabilities. Third, teaching practices in higher education shifted from traditional didactic models to interactive, problem-solving models that strive to establish critical thinking skills among students in preprofessional training programs. The combined influences of these broadly defined trends in policy, program, and professional practice are particularly relevant in higher education, where the forming of future professionals' values, attitudes, knowledge, and skills are critical for future practice and partnership with people with disabilities.

Teaching methodology in professional training programs is changing from a didactic approach to an interactive model that requires students to take responsibility for their own learning (6). Medical education first developed problem-based learning (PBL) to create a student driven learning model. PBL was since adapted to curricular content in several health, human service, and education disciplines. Beginning with PBL, four approaches to interactive and problem-solving approaches to teaching are briefly described in this paper. The strengths and contributions of each model are addressed and the person-focused learning model is highlighted as the focus of this study and context for participatory action research.

*Problem-Based Learning*. As stated above, PBL began within medical education to increase the application of medical theory and information with specific patient case studies and has since extended to nursing, occupational therapy, and other fields (7-11). Cockrell, Hughes, Caplow, and Donaldson described problem-based learning as a "collaborative learning approach" (12). Collaborative learning is premised on Vygotskian concepts that define learning as the social construction of knowledge. The cooperation and shared resources that take place in PBL learning reflect tasks in "real world" settings. These authors outlined six basic phases in PBL: (a) encounter with the problem; (b) free inquiry; (c) identification of learning issues; (d) peer teaching; (e) knowledge integration and (f) problem resolution. Based on their investigation of student's perspectives of PBL, Cockrell et al. found three key areas of student perspectives of PBL: ownership, group dynamics, and tutor feedback (12). Students reported a deeper level of understanding and retention in the PBL process compared to more traditional teaching approaches and increased awareness of team building skills. Students stated a preference for tutors who were non-directive and non-obtrusive. Students reported that the benefits of collaborative learning included: a) learning to become part of a learning community, and b) learning to speak the language of the community of professionals within the discipline.

*Inquiry-based learning*. Inquiry-based learning (IBL) uses a case-study process to encourage student responsibility for learning outcomes. Inquiry-based learning is similar to PBL in teaching methodology and includes presentation of case studies and the application of a problem-solving process that students use to identify relevant issues that require further research. However, rather than resolving the case through a diagnosis, IBL focuses on the inquiry process using issues that are relevant to the case (13, 14). As in PBL, students take ownership from the beginning, as in PBL and work in small, tutorial groups guided by a faculty member. The case is discussed and analyzed based on what information is known, further information needed, and the identification of learning issues that require further research. The cases provide a structure and format that guide students to

explore potential solutions to posed problems. Casebooks are now an accepted technique in preservice teacher training programs (15). As is indicated in PBL, the use of a case encourages group work that inevitably models collaborative communication skills found in the field. The paper case leads learners to apply skills learned to field projects (16). Students then conduct independent research and at a later session, present the results of their research that originated from the initial case study. Faculty members with the focus on critical analysis of relevant policy, program, advocacy, financial, cultural, facilitate summary and wrap-up discussion and community issues related to the case.

*Family-focused learning*. Family-focused learning (FFL) formed in the context of interdisciplinary education for health professionals to provide a model of direct involvement of family members in the teaching process (17). Family-focused learning follows the inquiry based approach through a series of sessions that begin with identification of issues around a particular family with an individual member with a disability, and close with student presentation of research issues related to the particular family that is participating in the teaching and learning process. The key difference in the FFL, compared to the previous models described, is that actual families and people with disabilities participate in the teaching process with faculty, interact with faculty and students throughout the development of case information to be presented and provide supportive critique to students in their work. Similar to PBL and IBL, the FFL model requires an initial session to present concerns and information that guide student inquiry. In contrast to the other two models, FFL involves actual family members who present the "family story" to students through video and written media. The development of the video is a joint venture for the family and participating faculty members that can require two or more sessions. When the family is satisfied with the video presentation, the tape is shared with students of several health, human services and education disciplines that identify key issues in a problem-solving process similar to the two models already described. Following completion of independent research, students prepare issue papers and present them to the family and/or individual for critique in a closing session. Family members and individuals with disabilities attend the closing session for the purpose of providing feedback to students on the scope of their work, relevance to their particular case, and quality in addressing the particular issue selected. As in the IBL closing session, faculty assist students in summarizing their analyses their individual research and relate students' findings to broad issues affecting families and persons with disabilities.

*Person-focused learning*. Person-focused learning (PFL) incorporates teaching and learning methods included in the previous models, but builds on elements found in each preceding approach. The elements of problem-solving and critical thinking that are hallmarks of PBL and IBL approaches are also essential to person-focused approaches. As in the FFL model, person-focused learning is designed and implemented with the participation of families and persons with disabilities. A new element is the service-learning aspect of PFL. In the PFL approach, students are required to complete a project that responds to needs and concerns identified by the family or individual (18). The involvement of persons with disabilities, families, faculty, and students in the development and implementation of the teaching experience produces a qualitative shift in teaching methodology and creates an action research model (4, 19-21). In the case-study approach, students respond to the issues presented for the primary purpose of advancing their own learning. In the person-focused model, students are placed in an interactive relationship with family members and individuals from the outset of the experience. The student learning goals, from the faculty perspective, involve: a) application of theoretical knowledge with real families and individuals with disabilities; and b) development of resources that respond to the needs expressed by families and individuals.

In the current study, the authors were concerned with the qualitative impacts of the PFL model on the people involved: students, families, and persons with disabilities. The unique features of the PFL model which incorporate problem solving in a real-life context and service to families and individuals require systematic evaluation. The assumption that direct involvement of actual family members and people with disabilities increases validity and thus applicability of the teaching process required empirical investigation and

| IHE | CSU Chico, CA | UOP, Stockton, CA | Disability Studies University of Hawaii |
|---|---|---|---|
| Course | Speech Pathology: AAC | Special Education: Methods | Disability Studies: Team Work |
| Level | Upper Division & Graduate | Upper Division/ Graduate | Upper Division & Graduate |
| Dept. | Speech Pathology | Special Education | Interdisciplinary Disability Studies |
| Students | 18 students | 40 students | 13 students |

*Table 1. Student participants in Person-Focused Learning at three universities.*

consideration of the ethics involved. In this study, the authors sought to systematically evaluate the reciprocal impact of interactive teaching on student learning outcomes and people with disabilities, specifically with people with disabilities in direct interaction with students for the duration of semester-long courses.

The foci of investigation centered on three questions:

1. What are student perceptions of the PFL process, both in the process of interacting with families and individuals and in learning outcomes?
2. What are family member and individual perspectives of the PFL process, regarding their partnership role in teaching students and project outcomes?
3. What are ethical and logistical considerations for the replication of PFL in human service training programs, particularly related to disabilities?

## Methods

The study was completed in the context of three interdisciplinary courses at three different university sites, with 71 students and 7 families including persons with disabilities. While course content differed across the three sites, teaching methods were similar. Teaching partnerships used principles of "Family Centered Care," in which family concerns drive professional interventions (22, 14, 23). Key steps in the teaching partnership included: (a) determination of family priorities; (b) adaptations to meet family and individual needs; (c) family input in project development; and (d) evaluation of completed projects by family members and persons with disabilities. Student learning outcomes were evaluated with qualitative surveys completed independently. Family and individual outcomes were identified through semi-structured interviews completed with the investigator.

The courses that provided the context for the study included a core special education course, an elective course in augmentative and alternative communication (AAC), and interdisciplinary teamwork course. Family members and individuals with disabilities participated as teaching partners with faculty members. Courses were located at California State University, Chico; the University of the Pacific in Stockton, California; and the University of Hawaii. Students who participated in the courses included three groups, shown in Table 1.

Characteristics of the seven individuals and families who participated in the study are listed below:

- Three adults, three children
- Communication disorders and physical disabilities in all subjects
- Two individuals with Asian/Pacific Islander ethnicity
- Five individuals were Caucasian

Course content and learning objectives differed across the three sites. However, key variables were held constant in teaching methodology. All courses included persons with disabilities and/or family members who participated in the design and implementation of the curriculum. The major requirement in each course included direct interaction with persons with disabilities and family members in the design and development of adaptive equipment or technology to meet needs identified by the individual and family.

Students engaged in a common process that included identification of needs by persons with disabilities and/or family members adapted from participatory action research (5, 1). Eight steps were completed in the person-focused learning teaching process. First, faculty developed

curriculum information about individuals in partnership with identified families and persons with disabilities. Second, students reviewed available information about the family and/or individual determine an initial developmental or environmental concerns identified by the family and/or individual. Third, student groups conducted brainstorming regarding potential family and individual concerns. Fourth, students prepared interviews based on guidelines provided by faculty. Fifth, students conducted interviews with individuals and/or family members. Sixth, the working group met to identify adaptation or support project based on results of prior information and interviews with individual and family members. Seventh, student groups presented completed projects to individuals and family members. Finally, student evaluations of the process and projects were completed.

The qualitative effectiveness of the person-focused learning process was evaluated by: (a) student perceptions of learning outcomes; and (b) perceptions of family members and persons with disabilities. Methods of evaluation included student's self reports and family/individual interviews.

*Self-Report*. Students were requested to complete qualitative comments in response to questions designed by the investigators. Questions addressed students' perceptions of the learning process and outcomes related to direct interaction with family members and persons with disabilities.

*Family/Individual Feedback*. Individuals with disabilities and family members were asked to evaluate their participation in the courses in a teaching/consultant role. Perceptions of these participants were also requested regarding the quality of student projects and interaction with family members and persons with disabilities. As the focus of teaching included adaptations and assistive technology, participants were requested to evaluate benefits and changes related to adaptations or resources developed by students.

## Results and Discussion

Results of the study are discussed in relationship to perceptions of student learning outcomes and impacts on family members and persons with disabilities.

*Student Problem-Solving*. Student responses to qualitative questions were analyzed to determine recurring themes related to investigative and problem-based learning in direct interaction with people with disabilities and family members. Analysis of student surveys identified seven themes: (a) attitudinal change; (b) authentic engagement; (c) critical thinking; (d) sensitivity to families and individuals; (e) collaborative teamwork; (f) preparation for inclusion; and (g) self–efficacy/skills to adapt materials. Examples of student comments are included below related to each theme:

*Attitudinal Change.*

"There are many things that disabled students are able to do…most important to focus on those strengths." 18c

"I realized how many aspects of a person's life can be affected by a disability." 18c

"It made me realize how difficult it must be to have a child with a disability, or to be a child with a disability; everyday actions are so difficult!" 19c

"I find myself constantly looking at isles in stores, toys, elevators, etc. to see how they could possibly be adapted to better suit the needs of children with disabilities—more awareness." 7c

"I think it helped me look at adapting equipment as a fun responsibility instead of a required duty." 8c

"It has helped me to realize that children with disabilities have a vast amount of needs, and that each child's needs are unique. Adapted equipment may still need further adaptations to meet a specific child's needs." 10c

*Authentic Engagement.*

"The hands-on work helped me to develop a better understanding of a family's needs and wishes for their children. Though most of all…learning the true-to-life reality of the processes involved in working with a family." 12c

"Actually making the adaptations brings more involvement and thus more interest, which lead to more learning." 12c

"I think with the case study, it is each to maintain the same frame of reference and not to expand on ideas or think about new things. With the adapted equipment, new ideas or problems are presented and we brainstormed." 10c

*Critical Thinking.*

"This assignment makes you think about aspects of disabilities that normally one wouldn't consider." 2c

"We had discussed the written assignment a lot,

even before we knew what the questions were. We were always thinking, how it would help B." 6c

*Sensitivity to Families and Individuals.*
"Meeting in an informal setting allows both sides of the team to get to know each other with out the pressure of a meeting…with the family relaxed we can start building relationships." 16c
"Getting to know the family was an important milestone for us." 16c
"It has made me realize that the parents are very important in identifying the a child's needs." 16c
"I thought it was very useful to ask T. [the parent] our questions because we had to know exactly what her situation was so the outcome would be helpful." 5c

*Collaborative Teamwork.*
"Yes, because we need each other's specialized skills along with knowledge and creativity." 14c
"It was a great idea to work in a group because everyone has different ideas which we can bring together. Then everyone has different talents which were utilized in the production process." 12c

*Preparation for Inclusion.*
"This is something I will have to do in my classroom so I appreciate the preparation." 2c
"To find different ways to teach someone the ABCs and how slow the song needs to be so that the child can learn." 9c
"It has made me realize that each child with a disability is an individual; helping each child can be done only if that child is looked at as an individual." 15c

*Self-Efficacy and Adaptive skills.*
"The most important part of this assignment was that it opened a door for me and pretty much told me that I had the potential to help any child with a disability." 3c
"I learned that I take my skills and abilities for granted. From meeting B., I realized that many aspects of daily living would be difficult for her, and in order for them to function at her level, more things would need to be adapted." 10c
"Yes, because it provides hands on time that I will remember more than any case study. It is also more fun than any case study." 9c
"I liked the developmental framework and the way this was all set up. It was very realistic to what we deal with in our real jobs and it was very hands on." 20c
"It makes me become more aware of the types of things; a lot of things that I would have never thought of." 13c

Family and individual interviews revealed four themes: (a) interaction with students; (b) self-validation; (c) support networks; and (d) alternatives to meet individual needs. Families and individuals commented that they would participate again. Table 2, below demonstrates representative feedback provided by family members and person with disabilities.

Ethical issues identified included the need to (a) respect individual choice in participation; (b) confidentiality; (c) honor individual priorities and (d) respect family differences. Comments provided by families and individuals at the completion of each class indicated the possibility

| **Theme Identified** | **Family Comments** |
|---|---|
| **Interaction with students** | "Having students come to our home was a highlight of the week for J., he looked forward to it all week." |
| | "Students gave S. attention and made us appreciate his importance." |
| | "I am getting braver to ask for what my son needs." |
| **Self-validation** | "I always knew that J. knows more and the students helped to document that." |
| **Support networks** | "It is wonderful for our whole family to participate with the students…going to the beach together was a first for us." |
| | "All of the time and support has given S. a chance to get out more." |
| **Alternatives to meet needs** | "The help provided by the class gave S. a way to communicate that he did not have before." |
| | "We want S. to learn with the other kids and he shows the book to every one who comes over." |

*Table 2. Qualitative themes and family comments regarding Person-Focused Learning Outcomes.*

of initial reluctance to participate. One parent commented that she initially was nervous when meeting the students for the first time, particularly due to cultural differences between them. However, this parent later reported that her feelings changed later after realizing how much attention and support the students demonstrated toward her son. This mother's comment highlights the need to honor individual family priorities that may be based on cultural styles, educational background, language differences, and other variables. Related to this is the need to respect and understand family differences and follow the lead of the individual or family to determine the most appropriate time and place to conduct interviews and project activities.

The results revealed positive qualitative student learning outcomes. People with disabilities and family members reported that their participation provided important benefits that included perceptions of increased self-efficacy and competence when interacting with students. Risks were not specifically identified by families or persons with disabilities, but inferred from their feedback. The responsibility to consider risk, which may include risks to privacy of participants, remains with the researcher who embarks on teaching partnerships with families and persons with disabilities. Comments provided by students in all thematic areas reported revealed increased awareness and respect for the life experiences of persons with disabilities and family members, thus establishing a foundation for ethical behavior in future professional roles with persons with disabilities, including teaching, service, and research.

## Summary

The results of the present study support the effectiveness of interactive teaching, specifically Person-Focused Learning, to promote student learning outcomes that demonstrate respectful and responsible professional attitudes and behavior with persons with disabilities and family members. The specific student learning outcomes were found in both cognitive and affective domains, as seen in students' evaluations of the learning experience. These findings have implications for preservice training of health, human service, and education professionals to establish a foundation for ethical behavior with human subjects in the career contexts of service and research.

The qualitative evaluation results of student learning outcomes indicate that involvement of persons with disabilities in the teaching process provides authentic learning that cannot be replicated with more traditional didactic methods. Further, involving family members in the teaching and evaluation process at all levels follows a participatory action research process and allows "checkpoints" for subjects to be fully cognizant of the research agenda and purposes. Thirdly, including people with disabilities in the research/teaching process strengthens validity as recommended by Kvale and Burns (2, 3). Further, reciprocity in the learning setting is achieved where students learn the needs of families and the value their knowledge when designing materials and technologies to assist them in the learning environment. The research participants are valued by the researchers and the students involved in the assignment and the student-made products are valued by the families.

The demonstration of a pre-service training approach that teaches reciprocal relationships with subjects is perhaps the key finding with implications for training future professionals in the area of responsible conduct of research. Not only did students demonstrate qualitative evidence of critical thinking in the learning process, the direct interaction with subjects in the action research model employed in Person-Focused Learning showed an effect on the students' sensitivity toward persons with disabilities and family members. The demonstrated effect on students' sensitivity with subjects could effect future professional ethics and conduct. While, further study is needed to determine attitudes and values that are directly related to the responsible conduct of research with human subjects, student attitudes toward subjects are considered a critical variable of ethical behavior. The question of what particular teaching model effectively trains professionals who are prepared to implement responsible conduct of research was only partially addressed by the present study. The attitudes and skills required for responsible conduct of research are clearly a constellation of knowledge and ethics that require further explication.

This qualitative study explored person-focused learning principles in several preservice courses and revealed positive findings for students and the families who shared their

stories. The "realness" of the learning setting allowed researchers to identify multiple learning outcomes and ethical issues when involving people with disabilities in a teaching setting and research endeavor. Bowen identified the need to strengthen internal validity through the integration of qualitative and quantitative research methodology (24). Further research in PFL is needed to a) specify affective and cognitive student learning outcomes; b) quantify changes in student attitudes; b) compare PFL teaching to other problem-solving approaches; c) identify long range impacts on student learning; d) develop guidelines for replication; and e) explore the use of PFL to teach responsible conduct of research. The philosophical attitude and the research model in the present study provide a framework for preservice education and further research to determine specific professional attributes that lead to affective, cognitive, and ethical foundations for the responsible conduct of research, particularly with persons with disabilities.

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